

A STUDY OF HIV-POSITIVE WOMEN IN DAR ES SALAAM, TANZANIA

An assessment on how Tanzanian women respond to getting their HIV-diagnosis, how they cope with being infected, and how they are treated by people in their local society. Additionally a collection of reader's feed back on FEMINA'S two booklets, "*Living positively with HIV/AIDS*" and "*AIDS in our community.*"



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Supplement

Interview number 11

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ABSTRACT.

Objective: To investigate how Tanzanian women respond to getting their HIV-diagnosis, to understand how they cope with being infected, and to assess how they are treated by people in their local society. Additionally to collect reader's feed back on FEMINA'S two booklets, "Living positively with HIV/AIDS" and "AIDS in our community."

Design: Qualitative design.

Setting: In the office of the organization FEMINA located in Dar Es Salaam, Tanzania, in the period 5.-25. of December 2004.

Participants: 11 HIV-infected women within the network of the organization PASADA.

Results: We found a poor personal motivation for actively seeking to find out one owns HIV-status, leading to a great delay in testing. The women felt it was hard to talk about HIV/AIDS in other than general terms, only letting close friends and family into their secret. Many were rejected by their family, treated with silence, disbelief or avoidance when telling. Even the families who accepted the diagnosis needed time to grief, before eventually becoming fully supportive. The women reported a manifest difference in the behaviors of those who are well informed and the more ignorant ones. All claims there is a lack of knowledge and information in their local society. People denying the problem is yet another challenge. Receiving the diagnose evokes a whole range of different reactions; shock, anger, concern, fear, bitterness and grief. The women we spoke to got help from different organizations after being diagnosed. From counseling they received useful advice on how to live positively. The women embraced this knowledge, and tried to live in the best way possible. FEMINA'S two booklets were regarded as very useful and sufficient.

Conclusion: Motivation for testing was experiencing illness at close range, or being tested when pregnant. The interviews all reflect the great stigma present in Dar Es Salaam. It is hard to be HIV-positive, and many were reluctant to tell it to friends and family due to all the misconceptions existing. More knowledge about HIV and AIDS lead to a more rational and fair treatment of those who have the disease, except for in those where fear leads to denial. Receiving the message that you are HIV-positive is overwhelming, and it takes time to accept it. NGOs and concrete information about the disease is very helpful in this process. The women were actively trying to take control over their life, and preserve their health. They reported a great need for more valid information and counseling to help the infected, and fight the stigma in the society.

INTRODUCTION

About the background

Sub-Saharan Africa is the continent most affected by HIV/AIDS in the world today and despite the effort put into the fight against this disease; the prevalence of HIV-infected is still increasing. 10% of the world's population is living in this region, and it is the home of approximately 64% of all people infected with HIV (11). In 2004 an estimated 3, 1 million people became newly infected, while 2, 3 million died from AIDS. However, in some East-African countries the situation is improving; for instance Uganda estimates a real decline in the incidence (6, p.179). In other countries, like Tanzania, the infection is unfortunately still spreading rapidly (11). Here the situation is alarming. The first AIDS-cases were discovered in 1983, and today the official numbers of infected range between 9%-12% of the population of nearly 36 million people. Quickly increasing, the number of HIV-positive rose from 5, 9% in 1994/5 to 8, 1% in 1999/2000. It is hard to gain absolute numbers though, as it is estimated that only 1 in 5 AIDS-cases is reported. (12)

To stop the negative development of AIDS in Tanzania, different organizations have started working here to stabilize the situation. The job is enormous and to change the situation, numerous interventions are needed. One of the most known organizations in Dar Es Salaam, PASADA *1, describes some of the main challenges: to reach the community with relevant and correct information, fight the stigmatization of HIV-infected people, encourage people to test themselves, distribute ARV medications (if they are present) and recruit and keep skilled health personnel.

*1: PASADA: Pastoral Activities and Services for People with AIDS Dar es Salaam Archdiocese (PASADA) The organization was initiated by a small group of HIV positive people in 1992. By 1994 there were 150 clients registered and a small dispensary was established with funds from the Catholic Church to provide medications. The current services include: medical assistance and routine treatment of opportunistic infections for 12000 registered HIV positive clients, including 600 children; laboratory services; a pharmacy; counselling; home-based palliative care; support to orphans and vulnerable children; a programme for Prevention of Mother to Child Transmission (PMTCT) and tuberculosis diagnosis and treatment.

Recently there has been an official political will power to fight the situation of HIV/AIDS in Tanzania. The Prime Minister, Frederick Sumaye, has stated that the pandemic is a national tragedy and that all stakeholders should be in the

forefront to fight the disease. One of the published political goals for 2005 is consequently to provide antiretroviral therapy (ARVs) to 220.000 people by the end of the year, and the government has earmarked 3 BNPs to provide ARVs to people living with HIV. At the most, this will only supply approximately 15 % of the infected population, and without further efforts this will leave the remaining 85 % untreated (11).

There are many other obstacles left to cross in addition to a shortage of medications. Even if the ARVs were present there is a lack of skilled personnel to distribute the medications, to inform the patients in a proper way, follow them up and counsel them on healthy living (6, p.211). For instance the mechanism of the disease are complicated and is best explained by a well educated person, and real health personnel are also much needed when teaching people about the effects of the medications. ARVs are given as a combination of three different drugs that each interferes with virus replications, and to bring out the maximal virus suppression, a high compliance is crucial. An optimal effect demands that the patients stay on the medications and use the required doses; in addition they have to eat regularly as many as three proper meals a day. Virus resistance is a highly feared problem and the selection of the recipients of ARVs should therefore be strict. Sadly this leaves out many potential users, because the criterions are hard to meet for many. The average Tanzanian is poor and can hardly afford a proper meal a day. Also, supportive surroundings are important, making it easier to cope with unpleasant side-effects without quitting the therapy. This is an issue, because many patients keep their HIV status secret to avoid stigma.

While the debate concerning how to fight the disease, and who should receive medications is ongoing, generations are dying. Mary Ash, executive director of PASADA, states that the official numbers of infected are only the top of the iceberg. What happens in Tanzania in the next 5 to 10 years will decide the destiny of the country. She fears that if no major changes occur, the disease will soon be out of control. AIDS related deaths in 2003 were estimated at 160,000, and the number is rising every year. At the moment, for many victims, the extended family is falling apart, and many are without anyone to look after them when sick. Mary Ash states that one of the main problems is to provide a quality service, that not only provides medications but also contributes to the other aspects of being HIV-positive. She will keep on working to ensure that PASADA retains its holistic approach and to integrate the ARV programme as a complement to the other services. To reach this goal, she acknowledges an ongoing need for major funding to support quality care, and the need to network with other service organizations to share the load.

Being interested in writing a paper concerning HIV/AIDS in Tanzania, we got in contact with our present tutor Johanne Sundby. She further introduced us to Minou Fuglesang, a Norwegian-Swedish anthropologist and founder of the organization Femina-HIP *2 (health information project). Femina-HIP has been active in Tanzania for the last 5 years. The aim of the organization is to educate people about HIV/AIDS. FEMINA produces two magazines called “Femina” and “Si Mchezo”, both free of charge. The target group is primarily 15-30 years old people. Some of the issues the magazines cover are different aspects of sexuality, reproductive health, how to live in a positive way, despite being HIV-infected and stigmatization. The articles are meant to contribute to improve the quality of life for the HIV/AIDS-sick people, and to prevent the further spread of the virus as well. Femina has also published two booklets, “AIDS in our community” and “living positively with HIV”, which will be distributed free of charge by voluntarily testing centers. It is important to Femina to get their readers responses. They want to verify if they have covered the most important problems when being HIV-positive. Using FEMINA as an entry-point, our study had a focus on gaining feedback on the booklets and looking into the situation of HIV-infected women in Dar Es Salaam.

*2: FEMINA: Femina is an organization which works in a range of different areas to promote information concerning sexuality, risk, HIV/AIDS and other lifestyle issues. The organization prints 92 000 copies of their FEMINA-HIP Magazine every three months and distribute free copies to more than 1000 secondary schools in Tanzania. Free copies are also sent to NGOs and youth clubs.

FEMINA TV Talk Show is Tanzania's first talk show for and by youth. The topics covered in the show mirrors the issues in the magazine.

Si Mchezo! (No Joke!) magazine is for rural, out of school youth who are not accustomed to reading. Every two months 45 000 copies are printed and distributed free of charge to communities in southern Tanzania.

HIP has also published a series of books about living with HIV and AIDS. Two books called 'AIDS in our Community' and 'Living Positively with HIV/AIDS' will be distributed via voluntary HIV testing centres. Another book tells the story of 20 Tanzanians who are living with HIV.

Members of the HIP team, drama groups and HIV positive activists regularly travel around in Tanzania to distribute information and educate people.

Sida and NORAD fund the FEMINA HIP magazine and USAID/ JHU fund the TV talk show.

A study of HIV-positive women in Dar Es Salaam, Tanzania.

Objective

Our objectives are the following:

To investigate how Tanzanian HIV-infected women responds to getting their HIV diagnosis, to understand how they cope with being infected, and to assess how they are treated by people in their local society. Additionally to collect readers' feed-back on Femina's two booklets, "Living positively with HIV/AIDS" and "AIDS in our community".

METHOD.

We chose to use a qualitative approach to investigate the situation for HIV-positive people in Dar Es Salaam. By using the structure of in-depth interviews we wanted to gather information concerning women's experiences with being infected. Our aim was to get a grasp of how they live and their way of handling their disease. A qualitative enquiry seemed to be the best way to gain this kind of personal information.

Being HIV-infected is a difficult issue in Tanzania. FEMINA is well known, and after years of working with people with HIV they have a valuable network within the infected society. This was fortunately passed on to us in our work. FEMINA introduced us to a woman living with HIV, who later set us up with the interview-objects. Working through the organizations own channels, their research-permit could include our project as well. In return we agreed to include a section about Femina's newly published booklets in our study.

The interviews took place in the period 5.-25. of December 2004. We interviewed 11 HIV-infected women between 23 and 53 years of age, who knew they had been infected for between 2 and 14 years. All were widows, except from one. They were all receiving help from PASADA, like free health care, clothes and some food. The women were primary caretakers and breadwinners in their families, but they were also poor. At average, they provided for about 3 persons, including their own or other relatives children, parents or other family members. This means they are low-income women, and most of them had a low educational level. 2 completed secondary school; 1 ended in form two but never ended secondary school. The rest had a maximum of primary school. (Standard seven.)

After several meetings with the staff in Femina, our original questions were revised and we worked out a new pilot-interview guide. This was tested on three HIV-positive, low-income women from the organizations network. From these women's responses, the interview was further adjusted to make the questions understandable and relevant for them and their like. This process proved to be valuable, since some questions we thought appropriate turned out to be offensive to some. We were told that to ask about a woman's marital status could imply that she got the infection from someone else than her husband. This is just an example of how difficult it is to talk about this issue, and we had to make several changes. In the end our final interview-guide contained three main headlines, in addition to a section about Femina's booklets.

When the final interview was set, we started on the main investigation. We worked together with a 26 years old male, freelancing anthropologist employed by Femina. He was to interpret our questions into Kiswahili, and translate the answers to English. All the interviews were recorded, to keep the data intact. The interviews took place in Femina's office, being anonymous ground, in which we hoped the women could speak as freely as possible. Femina is a well-known organization, and by using their office we tried to signalize the seriousness of our study to the women. During the first interviews we were present; to ensure that they were carried out in the way they were intended to. At the same time we tried to assess the validity of the questions. If a question gave less information than we hoped for, we added questions to elaborate. When a question repeatedly gave less insight than it was meant to, we discussed it with our research-assistant and reframed it. This was also based on full transcripts from the recorded data. After 5 interviews the final structure was set. From now on our assistant was fully capable of doing the interviews without us being in the same room. In the end we had 11 interviews on tape, each between 55 and 90 minutes long.

MAIN CONTENT OF THE FINAL INTERVIEW.

From our objective, the interview was divided into 4 main sections. Each section focused on a separate issue. We were told that few people in Tanzania are aware of their HIV-status, and as an intro the first part of the interview handled what had motivated the women we spoke to test. Furthermore, it was meant to provide a personal profile of the interviewees. Next, we wanted to explore the stigma as a background to understand the following part; namely the different aspects of reactions when receiving the HIV-diagnosis. In part 3, we asked in which ways the women coped with their disease. The last section is about the booklets, and collects some of the reader's feedback. Our findings on these matters are as following.

RESULTS, CONCERNING TESTING.

The women in our study were tested when pregnant, when getting sick or when experiencing illness or death in their surroundings. Pregnancy as a reason for testing-intervention has been a part of a national screening project started in 1990. This has been part of a governmental effort to map and further prevent the spreading of HIV in Tanzania. First, when the project was started, they screened blood donors. Soon the project was extended to include pregnant women as well. Apart from this, hospital resources for screening have been scarce, and they seldom offer to test their patients unless they have manifest symptoms of HIV/AIDS. (3)

Our findings are that 7 out of 12 of the women we interviewed had been sick prior to testing, 7 were advised from either their doctor or a close friend/relative. 2 were tested when pregnant and 4 tested themselves after a relative or friend died from AIDS. 6 got tested in a hospital, 4 at PASADA and 1 at ANGAZA. *3

*3: ANGAZA: Angaza, a program established by USAID in 2002 to promote quality HIV/AIDS counselling and testing services in Tanzania. Angaza has established voluntary counselling and testing services at 45 sites in all of Tanzania's 21 regions, and more than 200,000 first-time clients have been tested. Those who test positive have the option of joining post-test clubs offered at the sites to receive support and life-planning skills. Additionally, six Angaza sites now offer services that help prevent mother-to-child HIV transmission.

According to our interview-objects, it seems like it is first after having lived with disease at a close range for a while, and having personal encounters with its consequences, that they got tested.

What was the motivation for taking the test?

"Because I was in the bed for so long and I was tired. I just wanted to know about my health status once and for all"

Interview 1

"My husband passed away in 2001, it was June. In December I started getting ill and then I decided to check my HIV status because the way I saw my husband suffered, I suspected it could be AIDS"

Interview 10

None of the women we spoke to got tested without experiencing own or close relative's illness.

Two important reasons for this could be a lack of easily accessible testing facilities in the community, or a missing personal motivation for actively seeking to find out one's own HIV-status (6, p. 324). Most people know that medications are only available for few, highly selected groups, if at all (6, p.211). To many, getting a positive test-result does not change anything, because they can not afford to eat more, work less or buy medications. In such a setting, getting the HIV-diagnose might seem pointless, and only a way to add another burden. This may partly explain why only about 5 % know their status. One of the women told us she was asked to test as part of a screening-program of pregnant women when attending a routine check-up;
"In the beginning, we were 40, but only 16 agreed to get tested, and in the end only 4 of us received the result....."

STIGMA IN THE SOCIETY.

When planning the study it soon became obvious to us that HIV/AIDS is a controversial theme. We were advised to choose our words carefully, and to keep in mind that the disease evokes many different reactions. This ambivalence is reflected in our material, finding that only two of the women we interviewed spoke freely about their own disease, and this was first after several years of silence. The others spoke of HIV as well, but only in general, not mentioning their own health problems. All the women described a major difference between talking about their private health and HIV/AIDS in the community, experiencing negative reactions when telling about own disease makes it hard to be open. Several of our interview objects educated other people about HIV, but were reluctant to tell that they themselves were infected.

"...I can speak without mentioning that I am HIV-positive. When you tell people you are positive, they stigmatize you. Many associate AIDS with death. It is painful to know that you are going to die. People try to escape that pain by not talking about it."

Interview 2.

"...I think they take it as something shameful because it is transmitted sexually in most cases."

Interview 1.

This fear of stigma is the reason why the women are so selective when choosing who to tell that they are infected. Only trusted family members or close friends are informed.

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However, telling is a very hard thing to do, and many waited for a long time before including anyone at all into their secret. 4 of the women have not even told their own children. They say it is because they find them too young, and due to fear of their reactions.

How did you go about telling people?

“It was not an easy thing to do. It took me a year to tell a soul about my health status. Then I thought people needed to know because there will be a time I will need them to take care of me. Then another task came, to select who I should tell.”

Why was it that difficult?

“I thought that if I told anyone they would discriminate me. It took me that long to tell a soul.”

Interview 1.

The interviews all reflect a great stigma existing in Dar Es Salaam, and to be HIV infected has implications on several levels, like getting fired from your job, losing your friends and being rejected by your family.

Several women report that even when selecting who to tell carefully, they experienced to be rejected by close family.

What were people's reactions to you getting diagnosed as HIV-positive? *“My father's reaction was too disappointing. Just imagine my father who said therefore I am of no use. The next moment he threw me out of the house claiming he can't stay with a walking dead body.”*

Interview 8.

Others experienced not blunt misbehavior, but were treated with silence, disbelief or avoidance. Being positive puts a risk on the women's income as well. This is not only due to diminished working capacity when sick, but also because of the stigmatization. Some people are not interested in working together with someone who is infected, and many do not dare to buy food or clothes from an HIV-positive person in fear of getting infected.

Fortunately, many families are supportive after all, but receiving the message is a great burden causing shock and a lot of grief.

How did your mother react? *“She was sad to be honest, but she was old enough to understand. Therefore the next thing she said was that she will be there for me. And she has kept her words, I really appreciate her support.”*

Interview 6.

Even when the final result is support, it often takes some time for the people included to accept and understand the problem. In this period many of the women felt left alone.

How did you go about telling people? *“It was a bit hard because I was asking myself if they are (her children) old enough to understand or not. But I told them after a year what was going on. The oldest was in standard four.”*

Do you remember exactly how it was? *“I called them during the evening and started explaining to them every little thing. And it was a hard evening for them, but slowly they became comfortable with the situation. Now they can even joke with me that I am getting younger.”*

Who else did you tell? *“After another year I called my relatives in a small party at home, it was during Christmas, and I told them I had an announcement to make, because I am not sure if we can be able to meet again at another Christmas. Then I told them the whole story.”*

How did they react if you remember? *“Everyone had his/her own reaction. Looking aside, others looked at me, unbelievably. I wanted to see who would be able to look after my children when I am gone. Then my young brother said he would look after them, his wife was ready too. But unfortunately she died later on.”*

Interview 5.

To avoid negative and stressful reactions some women chose to tell only the other people in the HIV-network, where they knew they would be accepted. The members of the network are trained and know the facts about HIV and AIDS. The interview included some questions about the level of knowledge in the society, and we asked to what extent information changes people's attitude towards the women we interviewed. We found that knowledge influences the way people treat HIV-infected a great deal. The answers show a manifest difference between the behaviors of those who are well informed and more ignorant ones. All but one claims that the amount of information and knowledge in the local society is too poor. There are many myths about the disease, and this often leads to misbehavior. A persistent incorrect idea is that there is possible to tell who is infected by merely looking at the person.

“I think many believe that persons living with HIV can be identified by just looking at them. For those who don’t show any symptoms, they think he or she is OK.”

Interview 3.

Another misconception is that the virus is easily transmitted by normal everyday contact, like shaking hands or being in the same room. In general, misinformed people treat the sick and HIV-infected women poorer than those with a lot of knowledge about the disease. The educated keep close to them, knowing how to protect themselves. There seems to be a lot of fear among the ignorant, and fear is also likely to contribute to a tendency of denial. Two of the women stated that the main problem is not poor access to information, but a resistance to honor the facts. They believe many people find comfort in minimizing the dimension of the problem, and because of this people are not interested in learning more about HIV and AIDS. Denial is a natural psychological defense-mechanism, often occurring when one is scared. This avoidant conduct once again reflects that people associate HIV with death. Other reasons for not taking precautions, even when educated, are that the first priority to many is to survive the day. The problems of HIV lie in the future; many people don’t make long term plans and are most concerned about today’s income. (6, p.324).

What is the level of knowledge of HIV/AIDS (in your opinion) in your local society? *“I guess as days pass by, they begin to understand about HIV/AIDS, although there are a few who still refuse to agree that AIDS is out there.”*

Interview 10.

“....sometimes they even pretend that they don’t know what is going on. The other day I was on TV. I overheard them talking about me, but they can’t tell me to my face. Not even shoving me that they know my situation.”

Interview 1.

So, the myths and the lack of knowledge that contribute to inappropriate treatment towards the HIV-infected is only part of the problem. The interviews described the contours of a viscous cycle where the ignorance breeds the myths and leads to denial which causes risky conduct. If you believe in the misconception that you can tell who is HIV-infected by their appearance, the necessary precautions to avoid infections are not taken. This partly explains why people have unprotected sex and make themselves vulnerable to infection. It seems like many people are not able to deal with the problem in a rational way.

“I think people know about HIV/AIDS but they don’t want to listen. For instance if you advice a person to go and test there will be a fight between the two of you because they don’t even want to think that they could be infected.”

Interview 5.

RESPONSES TO BEING DIAGNOSED WITH HIV.

Emotional and cognitive.

The seriousness of the disease in itself, held together with the stigma in the society make the diagnosis brutal to receive. The message evokes a range of emotional and cognitive reactions. Chock is one of the more common feelings. Although many had lived with a suspicion for a long while because of experiencing physical symptoms of illness, the final test-result were still agonizing. Even those who were not surprised at all got scared, because the disease is so close related to death. Being HIV-positive causes a great concern about the future, especially when thinking about leaving their children. Just as the women described how friends and family needed time to accept the reality, the same applied to them. But eventually, they learned to cope with their new situation.

Can you describe your reaction to testing positive? *“For me, because I saw my child suffer and my husband die, I was not too surprised when they told me I had HIV. However I was angry in a way that I regret, like maybe the situation would not have been like this if I was not married to him (my husband). But I knew it is as God wishes, and there was nothing I could do about it.*

What did you think? *“I said to myself I had to commit myself to God and make it up to him. I thought about praying and asking for forgiveness if I was sinning in the past, a lot of thoughts I had, you know.”*

Interview 6.

Apart from chock and grief, anger is also prominent in almost half of the interviews. One woman was overwhelmed with bitterness, and felt life was unfair. Being sexually precautions, she found it likely that she was infected while caring for her sister. She thought that her new situation was highly undeserved. This feeling of unjust was shared by the others. They felt punished for their husbands risky sexually behavior and betrayal. One even tried to commit suicide.

What did you think; I mean what came into your mind? *“It was all about death. And I tried to poison myself, can you believe that? I was thinking I came from my parents without HIV, I gave my husband two children and now he gets me into this mess, I said I would rather die.”*

Interview 9.

This information corresponds with the information we got at PASADA. It is common that the husband brings the disease into the family, while the women are the one who get tested.

“Men infect the women-wives and girlfriends- who thereafter transmit the virus to their children.” (3).

Men seldom test themselves, and if they find out that their wives are positive it is not uncommon that they leave their family if they are well enough and start a new one at another place. This makes one of the greater challenges for the organizations to make men more active in the fight against spreading the disease. It is more accepted and common for men to be promiscuous, and the women traditionally have little saying in when and where to have sexually interaction*4 (6, p.51, p.151). Knowing that their men were the only possible source of infection, many of the women we spoke to felt victimized by someone else’s behavior. *4: See section about changes in sexual behavior.

“Since I picked up the virus from my own husband, while I was indoors and never saw another man, I hate sex to death. I decided to never have sex again, and God will help me I believe. Men are not faithful, and they are liars and most of all, they will ruin my life and my children.”

Interview 9.

Help seeking and counseling.

Being diagnosed with HIV has implications for the rest of the patient’s life. Sooner or later the person will get sick, and the working capacity and economical premises will be affected. The women we spoke to were a vulnerable group, especially economically. None of them were employed now; they were all doing their own small business, this leaving their income completely dependent on their own effort. In Tanzania, as in several African countries, there exist no governmental arrangements of economical compensation when a person gets sick and unable to work (4, p.26 and 6, p.210). This leaves less food on the table, and forces the other family members to contribute. Because of this many children are unable to attend school. There is an estimated 1, 5 million of working children in Tanzania. 77% of all children start, and about half of this group complete primary education. Only 7% proceeds to secondary school. (3)

According to the government, primary education is supposedly free in Tanzania. However, many families experience that schools require school-fees, in addition to different expenses like uniforms and books. On top of this, time spent on school is lost working-time, maintaining the vicious cycle of the poor staying poor and without higher education. (5, p.3)

In the setting of becoming unable to work, the interviewed women are left to the help and support from other people and organizations. Many of the health-clinics in Tanzania are run by NGOs, (non governmental organizations) and in our study the two most prominent were PASADA and WAMATA*6.

*6: WAMATA: Walio Katika Mapambano Na Aids Tanzania (WAMATA), Swahili for “Those battling against AIDS in Tanzania,” is a national grassroots membership organization comprised of people from all walks of life. They provide HIV/AIDS prevention education, training on the care of people living with HIV/AIDS, and school materials for needy students. This grant to the Sengerema branch of WAMATA is covering the educational expenses of 103 primary school and 18 secondary school children and providing vocational training for 5 youth. Funding also enables WAMATA Sengerema to pay for emergency food and medicine for 63 families affected by AIDS.

Muhimbili hospital is also used by many for testing, but it has limited capacity beyond distributing pure medical help.

As stated in the method description, our focus-group all received help from PASADA. The only criterion for being included in PASADA’S network is to test positive. PASADA has a good reputation, and to be in the network is a privilege. We found a general agreement that the help and support here were very useful and sufficient. First of all counseling is given prior to and after testing. Furthermore they canalize contact with other NGOs, and offer a network with HIV-infected people. Especially the network seems to be crucial to the women’s wellbeing. Many women find comfort in sharing their problems, and experiencing that they are not the only one having this problem. It gives great psychological therapy to meet others in a similar situation. In addition to this emotional support, PASADA also helps the women with practical difficulties. This holistic approach is a deliberate strategy from the organization, and proves to be a valuable combination. (1)

What did you do? (After receiving the diagnosis.) *“Then I decided to join the network. It helped me a lot because everyone tells their story, and we comfort each other. Then you know others have harder times than you, and then you give yourself hope.”*

What did you think about the help you got? *“It was good, and that’s what helped me to live the life I am living right now. You know, the most important thing is to accept the situation, and the counseling helped me to do this.”*

Interview 11.

One woman even describes how she got help from PASADA claiming back her properties from her ex-husband.

The women we spoke to were fortunate to be in the PASADA network, though still struggling for their daily income.

COPING STRATEGIES

From what we have learned from our study, being HIV-positive in Tanzania holds a very bad prognosis. Without treatment the immunity system deteriorates quite fast, and the body becomes more prone to different infections. Being a poor, low educated woman, a solitary care-taker of many children and living in a society where the official welfare system is close to none existing, there is a limited number of strategies to choose from to gain control of the situation. So far the society has failed, and is failing, to effectively help its victims of HIV, leaving the affected to their own methods of surviving in the best way possible. In contrast if you get the diagnose HIV in an industrialized country, it is not synonymous with a death sentence. Here the life expectancy of an HIV-infected person is close to the rest of the population. In Tanzania it is still a fast developing, deadly disease to most.

From this background, we wanted to look into the women’s private ways of coping. We wanted to learn what they were able to do, and what they actually did, with the resources available.

COPING WITH PERSONAL HEALTH

We found that all the women we spoke to were well informed when concerning how to take care of their health. They revealed detailed knowledge about how to avoid re-infections, for example not sharing blades, needles, soaps and tooth-brushes. When taking care of others, they were careful to use gloves.

Do you know of any other ways to prevent spreading the virus?

“Yes, for instance to not inherit a widow, stop female circumcision, blood transmissions and sharing blades.”

About female genital mutilation, how can you avoid that?

"It has to stop because they use the same instrument to circumcise many women. Because apart from transmitting AIDS it also deprives women of their sexual rights."

Interview 6.

All the women were more aware of physical symptoms of disease now than before receiving the HIV-diagnosis. Via PASADA they have been trained well, and they know the importance of seeking medical attention. They took it seriously whenever they felt sick, and without hesitation they immediately run to the hospital. All but one stayed calm, and instead of having a great emotional reaction, they acted rationally when experiencing symptoms.

Are you more aware of physical symptoms of disease now?

"Before I tested for HIV I thought of fever as fever and not as a symptom of HIV. Now I am very aware of symptoms like diarrhea, fever and boils, and I run to the hospital whenever it happens. I also understand that it is possible that my body immunity is decreasing."

What are your emotional reactions to symptoms of being ill?

"If I wake up in the morning and find the symptoms then I know I have to go to the hospital."

Don't you get like upset, worried or something?

"I will get worried only if the problem persists for a long time despite treatments because I will know my immunity is too weak and I can't survive anymore."

Interview 8.

The women were careful about their health, and they tried to take care of their bodies in several ways within their limited living premises. Their answers showed that all had made some efforts to change their way of living. The majority took time from work to rest and regain strength, making this their number one priority. All the women were also aware of the importance of eating sufficiently. The limiting factor keeping them from eating healthy was their economy.

How do you take care of your health nowadays?

"The way I take care of my health is to make sure I eat as healthy food as I can compared to what I earn. I also try to get away from all the thoughts like that I am going to die soon, and most of all I go to the hospital every time I don't feel well."

What are your eating habits nowadays?

“I have the appetite, I thank God for that, but what limits me is the ability to afford healthy food. When I get enough to buy it, I do it. I know how important it is to me. Basically it hasn’t changed a lot because I have HIV now.”

Interview 10.

Other ways to stay strong were to keep away from alcohol and cigarettes. The women also knew the importance of physical activity, and most of them managed to get good exercise via their work. Their different kinds of small businesses involve walking a lot.

Three saw a doctor on a regular basis, the rest only when sick. Most of them had check ups and counseling at PASADA.

Nine of the women knew their CD4-number. Only one woman, number 5, received ARV-therapy. Four had a CD4-number below 200, but were still not receiving any medications.

Do you use any medications, like ARVs or something?

“No, the last time I went to Muhimbili hospital they said they do not receive new people in this roll. We have to wait for the next round.”

Interview 10.

It could be that the changes the women made to their life seem small to an outsider, but in reality they reflect the women’s great effort to change their way of living. For example, taking some hours or a day off from work puts a lot of stress on the economy of the women we spoke to. Within this action lies an apparent strong will to make the best out of the situation. The women we spoke to had kept a fighting spirit, and to a great extent they had accepted the terms of their disease. In general, the level of knowledge among the women was quite high, and they were actively trying to maintain or improve their health situation.

CHANGES IN THE SOCIAL LIFE.

When it comes to changes in social interactions, the interviews show the same tendency as already described in the section about stigma in the society.

The women tried to keep a low profile after they were diagnosed with HIV to avoid negative reactions. The two most prominent strategies in achieving this were to go on living as before, or to limit their social activities. Living as normal as possible or keeping people at a safe distance made it easier to keep their status private. Three of the women explained how they spent most of their time with new friends within the HIV-network.

Has your HIV-status changed the way you interact socially?

“I try not to give people the impression that I have HIV, and therefore I try to maintain the same interactions, you know, most of my friends do not know, although some of them suspect it. I don’t know if I have changed a lot.”

Interview 11.

One woman became more religiously active, and increased the time spent on praying. Another made resting a priority rather than seeing friends.

Has your HIV-status changed the way you interact socially?

“Now I don’t even think about a luxurious life, like going out and have some drinks. I don’t even drink soda, maybe juice or water, and every little thing I get, I make sure it adds something to my wellbeing.”

Interview 4.

“I haven’t changed so much. In the first place I used to think so much about my life, my husband, divorce, because I was divorced before I underwent surgery, but during the counselling they told me not to think too much. I take a rest for like 8 hours everyday. This is something I never did before I was counselled. But I do other activities all the same.”

Interview 1.

CHANGES IN SEXUAL BEHAVIOUR.

Only one of the women had a sex-partner at the time of the interviews. All the others had given up on men and sex, for different reasons. Many of the women were aware of the danger of re-infections, and that different strains of the HIV-virus exist. Abstinence from sex were for those a natural way of trying to stay healthy.

So, you don’t have a regular partner now?

“What for? A partner to have sex with? I need a partner who will give me two beers, then I go home, that’s it. I don’t want to weaken my immunity. My doctor advised me to be careful because he knew men will want to be with me and I respect his advice.”

Interview 9.

Most of the interviewed felt that being HIV-positive excluded them from engaging in sexual activities. Resting, eating, working and seeking medical attention are factors controlled by the women themselves, whilst sex predominantly is the man's domain. We found that within a marriage it is traditionally the male who decides on when, where and how to have sex, including whether to use a condom or not. Many women are depending on their husbands' income, and are therefore afraid of denying him what he feels is his rights.

Did you use a condom? (When you were married.) Do you have the power to decide when or where to have sex?

"No, my husband would not allow that, although I tried to convince him. I was a nurse you know, we were given some condoms in the hospital, but they were never used. And there was nothing I could do about it. Therefore it is true that women find it difficult to decide on that matter, maybe your only options is to leave."

Interview 6.

Do you think women have power to decide whether to use a condom or not?

"Men have a lot of power over women, and women accept that because most of them don't have a source of income."

Interview 8.

Also single women find it hard to demand the use of a condom.

Do you think women have the power to decide when or where to have sex?

"I don't think they have the power."

Why is that the case?

"You know what? Other women use their bodies for business. If she refuses to use condoms it means she is going to miss money. Also in most cases women don't want to make men angry."

Interview 10.

GENERAL FINDINGS AND REFLECTIONS.

Our study of HIV-positive women in Dar Es Salaam unfortunately confirmed many of the ideas we already had prior to our stay. In addition, many of the challenges the women had to face we had not even imagined existed. We were aware that Tanzania is a poor country, with a consequently lower standard of life than most western countries. Still, it is hard to grasp the reality without actually

having been there. People's small businesses are fragile, and their income is completely dependent on hard work and good health. They have to depend on the kindness of others, including NGOs since the government offers little help. The country is not able to meet the demand for medications, trained health personnel and counselling.

Another aspect that made a major impression on us was how the women also had to handle the great stigma and all the myths existing in the society. It was shocking to learn how some families reject their own, considering them as already gone. The disease is strongly associated with death, and being diagnosed with HIV naturally produced a whole range of emotional reactions in "our" women.

Despite the seriousness of their situation, and all their hardship, the women appeared as very strong individuals. They showed great effort in making the best of the situation. Many of the women tried to make use of their own experiences to help other infected people.

And what should people learn from you?

"To be brave in every way possible, not only when it comes to HIV, but any further challenge. Like me and my father, we had a fight and I survived"

Interview 8.

"They should be brave, and ready to accept their responsibilities. I also wish them to have love for one another, especially for those who are ill."

Interview 11.

From our small study, it is not reasonable to assume that our findings are representative of an average HIV-infected person. The 11 women were quite capable persons, and this might partly be explained by the counselling they received. The counselling and the network gave them tools to handle personal as well as practical issues. This is a privilege, and it is not available to all HIV-infected. It is hard to predict how the women would have controlled their lives without it. Since we didn't know them before the counselling, it is impossible to tell how they lived prior to it. However, they were all very clear on the great value of an organisation like PASADA. So, whatever explains what kept them from not giving in, their personality or the counselling, the value of and need for further information and a network of people sharing the same problems is never the less obvious.

What can people learn from your experience?

"I would like to tell people that having HIV doesn't mean the end of the world. You can still have your dreams, and work hard to fulfil them." Interview 10.

“What I want to tell people is that if you have HIV, it doesn’t mean you are a dead body. Apart from that it helps a lot to tell people that you are positive when you are still healthy. People do not have enough knowledge, they will not believe you, but if you insist little by little there will come a time when they will accept you because time helps them to get emotionally prepared. Otherwise they will stigmatize you when they find out later.”

Interview 9.

THE BOOKLETS

In all the work of FEMINA a general belief is that more knowledge leads to healthier attitudes. Information is thought to be necessary in changing people’s behavior in a positive way and crucial to prevent the spreading of HIV/AIDS; (2). An example of just how powerful this conviction can be is the development in Uganda. Uganda is one of the African countries that has managed to slow down its own AIDS epidemic and from the middle of the 1990s this nation succeeded in altering their AIDS statistics, showing an actual decline in the HIV-prevalence. However, this achievement was not gained easily, and the fight against ignorance had been long prior to this. First after a huge governmental effort in addition to the participation of big organizations like UNICEF, Save the children and different NGOs, as well as local individual contribution, educating people was possible. Especially the involvement on a high political level also gave the program authority and helped to attain the positive results described. Consequently, Uganda turned their numbers around and eventually some hope was given where a depressive future was expected. In a time where the development of AIDS in Africa is in general negative, a story like this is especially valuable. Uganda shows that the disease can be beaten by a country without great economical resources. The story illustrates not to underestimate other means than mere distribution of expensive medications to get the disease under control. It stresses the importance of also influencing attitudes, keeping in mind that it was through distribution of valid and understandable information that Uganda succeeded in its effort. This example correlates with the original statement: Fighting ignorance change behavior and it points back to the work of FEMINA where this philosophy is held strong.

About the booklets.

FEMINA has many different channels for distributing their message, and it uses TV, radio and magazines to reach people. Consequently, when walking around

in Dar Es Salaam, the citizens seem to be familiar with the organization and its work, and copies of the FEMINA-HIP magazine can be found lying around in shops etc. Recently FEMINA has also printed two booklets, called “AIDS in our community” (1) and “Living positively with HIV/AIDS” (2). The booklets will hopefully further contribute to the education of the Tanzanian people, and they give detailed descriptions on how to handle HIV/AIDS, both as an HIV-positive and more generally in the local society. They include information about what AIDS is, common myths, in what ways the virus transmit, how to test yourself, how to practically cope with the disease and prevention of further spreading. The content is intended to summarize the main concern and questions of an average person and this means that it is important to convey the information in an easy comprehensible way, since many Tanzanians have poor reading skills. To reach as many as possible the language is kept simple, and the text is illustrated. To be an eye-catcher the wrapping of the booklets are adjusted to appeal to all the layers of the population, even those with the lowest education. On the front-page there are pictures and big headlines. The pictures illustrate several common situations a HIV-positive may encounter.

The booklets are inspired by a model called education-entertainment, where the materials are made easy understandable and “catching”. This is quite different from the traditional way of presenting scientific facts, where the material is written in a conservative way, that is; the facts are given in a straight forward way, without trying to make them easy accessible to all layers of the population. To give research an entertaining wrapping is often not done, even when this strategy probably would fit the target-group better. In many countries where this method is applied, it has however proved rather efficient. (14)

The interview and our findings concerning the booklets.

When doing the study on HIV-positive women in Tanzania, our analysis included not only reactions to being diagnosed, stigma in the society and eventual health preserving strategies, but we also asked for feedback on the two booklets already described, 1+2. The booklets were given to the women in advance, and had been read by all but one before we actually talked to them.*6

*6: All but one of the women received the booklets from a central woman in the network. This woman was the same one who recruited the women to the study.

By asking these questions FEMINA sought to get an idea on how the booklets were received by some of their readers, and preferably the answers would reveal honest opinions on how important HIV/AIDS issues are handled in the booklets.

FEMINA wanted to make an enquiry on whether the facts and info given in the text are adequate and if the message here is clear. Following is a more detailed description of what was asked, and the different responses we found.

In the two booklets FEMINA uses the strategy of education-entertainment, and to sort out if this method is effective, several of the questions were meant to map if the booklets are easy to read, catching, have good illustrations and if they manage to keep the reader's attention throughout the book. To inform people, it is not sufficient that the message is valid; it has to be catchy as well. This is a simple logic, if the facts are not read, they are not learned. Furthermore, an important element to gain feedback on was if the readers tended to share their new learned wisdom with others.

Perceived quality of entertainment and information.

Our findings on the quality of the booklets were uplifting. The feedbacks in general were very positive. All the women reported the booklets to be catching, and all but one finished reading all the pages. (This woman had not received the booklets as agreed, and following had not read it.) There was a general agreement among the women that the content of the booklets are easy accessible and written in a simple language.

Are they (the booklets) easy to read?

"They are easy, very easy I can say. They do not have any difficult words, just a normal everyday Swahili everyone can read."

Interview 6.

The stories are relevant and deals with everyday situations. They are kept strictly to the point and the sentences are short and direct, and from the responses we got, this makes the material well adjusted to a group with a rather low educational level.

Do they (the booklets) give enough information?

"Yes, also the stories are not too long, but enough for people to understand, you know, long stories make one tired."

Interview 5.

According to the women the illustrations also fulfill their intention. Even if you can not read, the holder of the booklet will still learn from the pictures. There are several cartoons, and all the women reported that the drawings are useful in conveying the message.

What do you think of the illustrations?

“They are good. The cartoons educate in practice. You see exactly what they mean.”

Interview 8.

FEMINA also wanted to know what issues are most interesting to their readers, and we therefore asked which sections immediately caught the attention of the women.

The most popular sections were the part about ARVs, how to write a will and how to live in a positive way when being HIV-infected. How to safely care for HIV-infected was also a topic many of the women mentioned. Some were especially interested in practical advice, for instance about how to be sexually active in a safe way or what kind of food to eat to preserve their health.

“There was a topic about being lovers without having actual sexual intercourse. I did not know that this was possible, and I liked it.” Interview 6.

“I liked the part about food. I wanted to know how to live, what to eat and about sex.....” Interview 11.

One reports that seeing familiar faces on the front page caught her immediate attention. Another one said she liked the title “Living positively...”

All but one of the readers passed on the booklets to close family or neighbors after finishing them themselves. This shows that they found the content important to share, and worthwhile to read for others as well. All in all, the intentions of the booklets to be entertaining and catchy seem to have been fulfilled, and the fact that all the women read all the pages reflects that the booklets are easy enough to read.

Do they (the booklets) give enough information?

“They give information, they educate and they also entertain for some people. They do not bore.”

Interview 8.

Perceived adequacy and validity of the information in the booklets.

Catching the attention of the reader, and keeping it, is only two of the qualities the booklets have to hold. They should be entertaining, but this is in itself not enough to educate in a proper way. As well as entertaining, the content has to be of high validity and full of facts. We wanted to know if the women learned

anything new from reading. Only two women said they found something they did not know beforehand, respectively about STDs, stigma and how to write a will. Even though the rest of the interviewed told us they did not learn anything new, they still found the information useful.

Did you learn anything new from reading the booklets?

“No, I guess nothing is new, but they are important.” Interview 10.

“I already knew most of the things in the booklets, but I still enjoy repeating and reminding myself of different aspects of HIV/AIDS.” Interview 4.

The content of the booklets have to be sufficient, so furthermore we asked the women if they thought the booklets covered all important aspects of HIV/AIDS. The general agreement was that 1+2 gave enough information. Most of the women did not think there was anything left out, though when asking more closely, many had suggestions on topics to be elaborated on or added. More information concerning stigma, how to live positively and how to care for an infected person was wanted. The tendency is that the most popular sections correspond with the subjects they wanted to learn even more about. The issue about how to have safe sex and how to protect oneself from being exposed to the virus were repeated.

What more information do you think would be valuable for people in your situation?

“I think the booklets have enough information..... (....)...maybe more information about sex because that is the source of the problem. Myself, I did not know it is possible to have a lover without having sex/penetration.”
Interview 6.

Any subjects you would like to learn more about?

“About condoms I guess. You know there are many things said about condoms, sometimes it is said not to be 100% sure, and others times it is said to be the perfect prevention.”

Topics you would like people around you to be more aware of, that you find difficult to discuss?

“The same about condoms. People need to look at that carefully, because they even say that if you can not abstain or be faithful, then you can use a condom. That shows condoms are the third option.”
Interview 8.

6 of the women would like to read more about ARVs. Several also stress the importance of testing oneself, and informing the surroundings if found positive to prevent further spreading of the disease. One of the women thought the most important thing is to be aware of your rights as an HIV-positive.

An uplifting finding was that the booklets succeeded in keeping the text realistic, and the readers could easily relate to the stories and the women found them useful. The different topics were perceived to be handled in a sufficient way.

How useful do you find the booklets?

“They are helpful; people living with HIV understand what they are talking about. Because what is written occurs to them everyday.”

Interview 5.

“They are very useful to us (HIV-positive), on how to live positively and they may also be useful to others because they can learn them to treat others when they are ill.”

Interview 10.

The layout and content of the booklets did not offend or provoke any negative emotional reactions. Most said it was okay to read them, one said it gave her relief and another one said they made her feel more comfortable about her situation.

CONCLUSION.

All the women had good use of the two booklets. Our study showed that the women felt the issues are well handled by FEMINA, the information is sufficient and valid, and the layout is appealing and interesting to the reader. A common wish was for a wider distribution, and to give the booklets to the villages and rural areas as well. There is apparently still a great need for more information, and the booklets soon became popular among the women and the people they shared them with as the women passed them on, finding the content relevant to anyone.

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